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de Groot, Nina; van Beers, B.C.; Decock, Lieven; Meynen, G.

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Accessing medical biobanks to solve crimes: ethical considerations

Nina F de Groot,[1] Britta C van Beers,[2] Lieven Decock,[1] Gerben Meynen[1,3]

[1]Department of Philosophy, Faculty of Humanities, VU University Amsterdam, Amsterdam, The Netherlands
[2]Department of Legal Theory and Legal History, Faculty of Law, VU University Amsterdam, Amsterdam, The Netherlands
[3]Willem Pompe Institute for Criminal Law and Criminology, Utrecht University, Utrecht, The Netherlands

Correspondence to
Nina F de Groot, Department of Philosophy, VU University Amsterdam, Amsterdam, The Netherlands; n.f.de.groot@vu.nl

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ABSTRACT

Millions of human biological samples are stored worldwide for medical research or treatment purposes. These biospecimens are of enormous potential value to law enforcement as DNA profiles can be obtained from these samples. However, forensic use of such biospecimens raises a number of ethical questions. This article aims to explore ethical issues of using human bodily material in medical biobanks for crime investigation and prosecution purposes. Concerns about confidentiality, trust, autonomy and justice will be discussed. We explore how to balance these concerns against the importance of crime solving. Relevant case examples of forensic use of medical biobanks show that requests by law enforcement to access biobanks are handled in disparate ways. We identify some core ethical issues and conclude that further research on these issues is needed to provide ethical guidance.

BACKGROUND

When a patient visits a physician and bodily material is obtained, the samples are usually stored for possible further use in the future. In the USA, human biological material of at least 178 million individuals is kept, estimated to increase by 20 million per year.[1] Also in Europe, biobanks house enormous amounts of biospecimens, such as the joint European BBMRI Biobank, accommodating more than 100 million human samples.[2] In the field of medicine, samples are routinely stored for research and/or treatment purposes, and include every possible bodily material, such as bone tissue, tumour samples, blood or sperm. A wide variety of medical biobanks exists; some are population biobanks for grand-scale research, others may entail small collections of rare tumour tissue.

One can easily imagine the potential value of these immense numbers of biospecimens for law enforcement; DNA profiles can be obtained from these samples which can be compared with DNA profiles obtained from a crime scene and, in turn, can be used for criminal investigation and prosecution purposes. Indeed, in various countries, medical biobanks have been accessed over the years for criminal investigation purposes, often in high-profile cases.[3–5] A striking example is a criminal investigation that took place in 2003 in the aftermath of the assassination of Anna Lindh, the then foreign minister of Sweden.[6] Lindh was stabbed multiple times in the chest and abdomen while shopping in a department store in Stockholm. She died in hospital the next morning while the assaulter was still missing. After authorities failed to match the DNA found at the crime scene with samples in the country's forensic genetic database, police officers went to the Huddinge University Hospital, which houses a large newborn blood sample database. This biobank, used to screen newborns for hereditary diseases, stored approximately 3 million blood samples at the time, comprising almost half of the Swedish population.[6] The chief public prosecutor requested the blood sample of Mijailo Mijailovic, a prime suspect in the murder case. The hospital provided the sample and soon a match was found between the DNA profile obtained from this sample and the DNA profile obtained from the murder weapon. Mr Mijailovic was arrested and sentenced to life imprisonment.[7]

It is unknown precisely how often law enforcement requests or obtains bodily material from medical biobanks, although it plausibly occurs infrequently. However, it is clear that over the years, forensic use (and attempted use) of medical biobanks has occurred several times.[3–5] Surprisingly, even though the ethics of forensic use of direct-to-consumer (DTC) genealogy databases has recently received much attention in the aftermath of the 'Golden State Killer' arrest in 2018,[8 9] forensic use of *medical* biobanks (FUB) has only been scarcely addressed in the ethical literature. There is extensive literature on the ethics of medical biobanks,[10 11] the ethics of forensic genetic databases,[12] as well as literature that critically questions the division (and examines possible flows) between those two.[13 14] However, we believe that a separate ethical discussion of FUB is much needed, because FUB *itself* literally crosses the boundaries between both types of genetic databases.

Moreover, it is important to have an ethical debate—and preferably ethical guidance—about this issue, especially because in the future FUB might occur more frequently, as technological advancements evolve rapidly. For instance, in the Netherlands, a draft bill has been proposed that aims to specifically *permit* FUB. We think it is essential that the issue is not solely discussed from a legal perspective, but also from a bioethical one, as medical professionals and institutions might be directly confronted with these issues. Also, ethical guidance might influence policy decisions, and ultimately legislation.

This article is the first article to offer a broad overview of the ethical issues related to using human bodily material in medical biobanks for crime investigation and/or prosecution purposes.[i] It

[i]This article explicitly does *not* focus on forensic genetic databases (set up for crime investigation purposes). Also, FUB in the context of (disaster) victim identification is beyond the scope of this article.

Table 1 Cases of (attempted) use of human biological material stored within a medical setting for the criminal investigation or prosecution of a suspect

Year	Country	Crime	Reason for access	Access	Kind of bodily material
1997	Australia	Incest	Evidence of incest through paternal testing	Yes	Blood (Guthrie card)
2001	UK	Knowingly passing HIV	Evidence of HIV infection of suspect	Yes	Blood or blood results (not known which of the two)
2003	Sweden	Murder	Identification suspect	Yes	Blood (Guthrie card)
2004	USA	Murder (multiple)	Identification suspect (via daughter)	Yes	Cervical cell material (Pap smear) from suspect's daughter
2005	Italy and France	Murder (multiple)	Identification suspect	Yes (of two individuals)	Tissue sample (most likely prostate tissue) and tissue sample from suspect's brother
2005	Norway	Bank robbery, murder	Identification (deceased) suspect	No (Supreme Court ruling)	Unknown
2009	Sweden	Murder, dismemberment	Identification (deceased) suspect	No (Court of Appeal ruling)	Cytological sample or tissue sample
2015	The Netherlands	Attempted murder	Identification suspect (through identification of the child)	No	Blood (Guthrie card) linked to personal details

draws on the existing literature concerning FUB and informed consent,[3] FUB from a legal perspective[15 16] and the comparison with general forensic genetic databases.[12 17] First, the strongly related concepts of confidentiality and trust will be discussed in the context of FUB. Confidentiality and trust are closely connected to the privacy rights of the patient, and are, as such, at the core of this ethical debate. Next, the principles of autonomy and justice, two relevant core principles of bioethics,[18] will be examined.[ii] In that process, several important case examples of FUB are used to reflect further on these issues. Finally, it will be explored how the impact on confidentiality, trust, autonomy and justice can be balanced against the importance of crime solving. This paper will present an international overview of publicly known case examples of the use of medical biobanks for criminal investigation purposes. As such, it provides the most extensive overview so far of case examples of FUB. It will become clear that requests by law enforcement to access biobanks are handled in disparate ways. We identify some core ethical issues and conclude that further research on these issues is needed to provide ethical guidance.

ETHICAL ISSUES TO CONSIDER REGARDING FUB

Confidentiality

Perhaps the most important issue that should be taken into account when discussing FUB is confidentiality. The justification of confidentiality can be made by relying on either a consequentialist or deontological line of argumentation. From a *consequentialist* perspective, the main problem is that an abandonment of confidentiality may damage the trust relationship between doctor and patient. From this perspective, not maintaining confidentiality might, for example, lead to people avoiding care or not disclosing relevant medical information to their physicians. This, in turn, can lead to a wrong diagnosis, inefficient treatment or public health risks, which might ultimately result in more harm than keeping confidentiality. According to the *deontological* perspective, one should maintain confidentiality because that is one's duty, irrespective of the consequences. A deontological argument might be based on respect for the patient's autonomy, privacy or a promise-keeping of maintaining trust.[19 20]

Furthermore, confidentiality is closely related to the concept of privacy. Privacy implies a 'separateness from others' and can be divided into two spheres: *spatial privacy*, which concerns non-access to one's physical or psychological integrity, and *informational privacy*.[21] Informational privacy is 'a state in which personal information about an individual is in a state of non-access from others'.[21] Confidentiality can be seen as a branch of informational privacy.[22] Privacy and confidentiality are not synonyms. Confidentiality does not only entail protection of one's personal information, but also protection of a *relationship*.[21] With respect to medical confidentiality, this concerns the physician–patient relationship.

As already indicated, central to respecting medical confidentiality is the accessibility of healthcare; everyone must be able to have non-restrictive access to professional medical help. Medical confidentiality thus aims to protect both the individual patient as well as society as a whole. The importance of confidentiality is reflected in numerous professional guidelines, in which it is considered a *prima facie* value. However, both the consequentialist and the deontological perspectives on medical confidentiality hold that under certain circumstances, exceptions to confidentiality are possible. From a consequentialist perspective, there might be cases in which maintaining confidentiality might result in more harm than breaching confidentiality, for example, when a physician might prevent a murder by disclosing her patient's plans. Within such a decision, all relevant consequences should be taken into account, including the consequences for the patient, the public and the societal interest. From a deontological perspective, confidentiality is in general regarded as a *non-absolute* duty.[18 19 21] Interestingly, the debate regarding confidentiality in the context of crime has traditionally focused on a possibility to breach confidentiality in the case of crime *prevention*, not for criminal investigation or prosecution purposes.

The tension between medical confidentiality and crime solving can be recognised in some case examples of FUB. One of them is the notorious 'BTK case' (for an overview of cases, see table 1). In this case, US police forces had tried for a long timeto track down a serial killer, but he could not be found. The unknown assailant, who murdered at least 10 people between 1974 and 1991, nicknamed himself BTK—'Bind Torture Kill'—in the many letters he sent over the years to newspapers and authorities. Decades

[ii]Beneficence and non-maleficence will not be discussed, because FUB does not involve a biomedical intervention.

later, a man called Dennis Rader was named as a suspect, but law enforcement did not have enough evidence to prosecute him.[5] Therefore, law enforcement decided to seize cervical cell material of Rader's daughter, kept in a university clinic, in order to compare it with DNA found at the murder scenes.[5 23] A partial match was found and subsequently Rader was arrested and convicted. He is currently serving a life sentence.

In this case example, the issue of confidentiality is perhaps even more important because it involves the bodily material of a family member of a suspect and not of the suspect himself. It can be argued that the informational privacy of the daughter's medical conditions is violated, as the *kind* of seized tissue sample already discloses a (plausible) medical condition; in this case, a Pap smear for cervical cancer screening. Indeed, this is a major issue when considering FUB: the bodily material stored in biobanks *in itself* constitutes very sensitive information. Based on the type of stored bodily material, one could infer the plausible medical condition of the donor. Whether the stored tissue would be a breast tumour, uterine fibroids or sperm, the material reveals a likely condition; breast cancer, myomata and subfertility, respectively. Although this information is not of direct interest to law enforcement, it can be regarded as an inevitable 'bycatch'—of a highly confidential nature. In addition to the sensitive nature of the type of bodily material, a broad variety of sensitive information can be derived from this material, such as parental links, genetic ancestry, (predisposition to) hereditary diseases, as well as information about someone's physical appearance, such as hair colour.[24] Furthermore, the physician–patient relationship between the daughter and her physician in the clinic might be damaged as she did not expect that her tissue material would be used to implicate her father. Thus, it is also a matter of medical confidentiality.

Correspondingly, empirical research suggests that people are concerned about confidentiality issues in the context of FUB. A US survey of 4659 possible participants of a biobank showed that 75% of participants were concerned about the 'government having their samples and information'.[25] In addition, 84% of participants stated that they found it 'important to have a law protecting research information from law-enforcement officials'.[25]

Like in the BTK case, another case also involved a family member. In Italy, police had tried to find for decades the chief of the Sicilian Mafia, Bernardo Provenzano. In 2005, the police still had no idea whether the notorious criminal was fugitive or had already died, until they received information that he had got himself treated for prostate cancer under a false name in a French hospital a few years earlier.[26] Police seized the hospital tissues of this 'pseudonym' and made a DNA profile, which they then successfully matched with Provenzano's brothers' DNA. Interestingly, they obtained this DNA from a blood sample of Provenzano's brother stored in a hospital in Palermo where his brother had undergone surgery.[26] The police now knew that Provenzano was most likely still alive and the search for him intensified. Eventually, he could be captured.

In contrast to the above-described cases, there are at least three case examples in which FUB was attempted by law enforcement but did *not* succeed because it was refused on the basis of medical confidentiality. The first one concerns a robbery case in Norway. In 2004, one of the largest bank robberies in the country's history took place in the city of Stavanger. In the violent armed raid, one police officer was killed. After an extensive investigation, it turned out that one of the prime suspects had died of cancer a few months after the robbery.[27] The police requested access to tissue samples of the deceased that were stored at the Aker University Hospital in order to compare them with DNA samples found at the crime scene. However, the hospital refused to provide the samples on the basis of confidentiality. The Norwegian Supreme Court, eventually, ruled in favour of the hospital's decision.[28] In its ruling, the Court stressed the importance of the right to privacy in these kinds of issues, both before and after death, because human bodily material can provide information about the person's genes, diseases and other characteristics 'now, and in the future'.[28] The court, thus, focused on its ruling on the notion of informational privacy.

The second example involves another Swedish case. In 2009, Swedish police attempted to solve a cold case murder. Twenty-eight-year-old Catrine da Costa had been killed and dismembered in 1984. Several body parts were found in garbage bags on different locations, although her head, one breast and genitals remained missing. Forensic investigation of the site where the bags were found led to the securing of some hairs of the alleged killer.[29] As DNA from the two main suspects in the case, a pathologist and a general practitioner, did not match with DNA from these hair strands, police turned to another suspect. This man, a butcher who had previously been convicted for murder and dismemberment, had, however, died in 1987. The Pathology and Cytology Department of the Huddinge Hospital stored tissue samples of the deceased suspect and these samples were requested by the public prosecutor.[29 30] When the hospital refused to hand over the tissue samples, the case went to court. The District Court of Södertörn initially permitted access to the tissue samples, but the Svea Court of Appeal annulled this decision.[29] Consequently, the tissue samples were never used.

A third case occurred in the Netherlands in 2015. In Amsterdam, a newborn of only a few days old had been left in an underground garbage container. As the container was full of trash, the newborn survived the fall into the container and was discovered by a passer-by. When attempts to track down the parents of the baby failed, the public prosecutor requested the Guthrie card of the baby, a blood sample used to screen for hereditary diseases. As the blood sample is linked to the personal information of the child, the prosecution intended to identify the parents through this specimen. However, the National Institute for Public Health, which stored the newborn blood samples, denied access on the basis of their medical confidentiality.

In some countries, legislation is in force that explicitly prohibits FUB, mostly based on arguments about protecting confidentiality. For example, both Finland and Estonia have a clear policy in this regard. Estonia, housing one of the largest biobanks in Europe,[31] established the Human Genes Research Act, which states clearly that the '[u]se of the Gene Bank for other purposes, especially to collect evidence in civil or criminal proceedings or for surveillance, is prohibited'.[32] Similarly, Finland has laid down the prohibition of using medical biobanks for crime investigation purposes in its 2012 Biobank Act.[33]

In contrast, in the Netherlands, a proposal for a Dutch Human Tissue Act was presented in 2017 which includes an article that would allow FUB for the investigation and prosecution of serious crimes.[34] The draft bill states that in balancing the interests of investigating and prosecuting crimes on the one hand, and access to healthcare on the other hand, there are exceptional circumstances in which truth finding and prosecution of crimes are considered as more important than protecting medical confidentiality. It is argued that this is the case when, among other things, the crime is very serious, such as murder or rape. The severity of the crime thus plays an important role.

In sum, the notion of confidentiality is at the core of the ethical debate regarding FUB. As we have seen in the case examples,

confidentiality is not limited to a living suspect's bodily material, but also to that of a deceased suspect. The different case examples of FUB have shown that there are profound differences in how confidentiality and crime solving are balanced against one another. An important factor is whether one takes a more deontological or consequentialist viewpoint. This issue will be further explored in the Discussion section.

Trust

Trust is highly valued in medical practice and is closely related to confidentiality. The notion of trust has been widely debated and various definitions have been proposed.[35 36] In several accounts of trusts, the concept of vulnerability is central; within the physician–patient relationship, often sensitive information is being confided by the patient, which leads to the patient having a vulnerable position in this regard.

Trust also entails *entrusting*; Baier's theory of trust includes the notion that a person—with accepted vulnerability—entrusts to another individual, a thing X, that is of value to her.[35] According to Hall's conceptualisation of trust, it is crucial that there is 'optimistic acceptance' of vulnerability, with positive expectations, and not solely trusting behaviour.[36] Thus, it is not necessarily the case that an individual who seeks care should automatically be considered to have some degree of trust.[36] For example, consider a country in which a fugitive criminal, severely wounded after being shot by a police officer, visits a physician for professional medical treatment, although he is aware that every doctor in the country will immediately report him to the authorities and he will face a lifelong prison sentence. In this case, we can hardly say that the criminal is trusting the physician; it is merely a matter of inevitable death versus a prison sentence. The act of the criminal visiting the physician does not constitute trust, since although the criminal is vulnerable, he does not have an optimistic acceptance of this vulnerability.

Some suggest that FUB might have a negative effect on trust.[3 6] When trust in the context of FUB is discussed from a consequentialist perspective, one might argue that FUB could negatively affect the trust in doctors in general, thus resulting in negative consequences, including that some patients might refrain from medical care. This, in turn, could give rise to, for example, an outbreak of infectious diseases. A possible counterargument is that this future vision is framed unnecessarily catastrophic: FUB will only affect the trust of those suspected of severe crimes, which is something that could be regarded as being taken for granted as it will only apply to a small (criminal) portion of the population. However, it is quite likely that these individuals would then avoid medical help out of fear they will be charged for their crimes. Would we be willing to accept such a consequence? One might argue that *even* if we would make the radical claim that a person who has committed a horrendous crime has no right to live, it is hard to accept him or her dying in tremendous pains without any professional medical help. Moreover, refraining from seeking medical care may not only apply to criminals; FUB might also deter other patients, who could reason that, somehow, in the future they may be sought by the police (because who knows which path life or politics will follow). Perhaps this is more likely in patients who already encounter symptoms of anxiety or paranoia.

FUB might not only affect the trust in medical professionals and institutions, but also that in medical research in general. It has been argued that a fundamental part of public trust in biomedical genetic research depends on research participants and patients knowing that third-party access to their sensitive information is strictly prohibited.[37] There are also some indications that FUB may affect the trust of the general public. For example, in the Anna Lindh assassination case, the debate about the question whether it was justified to obtain the blood sample of the suspect from the newborn blood biobank mainly revolved around the issues of confidentiality and trust. Some argued that the biobank should not be accessible for crime investigation purposes, because it is a matter of maintaining public trust.[6] In contrast, one of the members of the Swedish National Board of Health and Welfare claimed that it would not affect the public trust nor the willingness of parents to have their newborn screened: 'I do not believe that parents see their own child as a future murderer.'[6] She proposed to make it possible by legislation to allow FUB in the case of severe crimes and stated that 'we cannot have murderers (…) walking around in the streets'.[6] In this respect, it is of interest that in the year following the assassination of Lindh, 445 Swedes asked for the destruction of their tissue samples stored in the biobank, compared with only 17 requests up until 2003.[6] Likewise, in the aftermath of another case, much more blood samples were destroyed; in Australia, police seized multiple Guthrie blood samples of children during an investigation into alleged incest, in order to examine who was the father of these children.[38] A police officer went to the Perth hospital with a search warrant and received the blood samples.[38] The case evoked extensive media attention and public discussion which led to the destruction of all Guthrie cards in Western Australia older than 2 years.[39]

With respect to trust, another important distinction can be made; that between trust and trustworthiness.[36] Although they often go together, this is not necessarily the case. On the one hand, patients can trust physicians (or medical institutions) who in fact must not be trusted, and on the other hand, patients can mistrust trustworthy physicians. An interesting case in this respect is the Stephen Kelly case. In 2001, Kelly was charged for knowingly transmitting the HIV to his former girlfriend by sexual intercourse. For a conviction, the public prosecutor needed evidence that the suspect knew he was infected with HIV at the moment he met his girlfriend.[4] Therefore, the prosecutor requested access to a blood HIV test that the suspect had previously undergone. Kelly had himself tested as part of an HIV research programme in Glenochil Prison, where he was detained at the time. The research was set up because of heroin needle sharing in the prison. Later, a molecular research programme showed that a woman (who later turned out to be Kelly's former girlfriend) had the same HIV strain as the Glenochil Prison virus strain.[40] Backed by a court order, the prosecution obtained the HIV blood test and Stephen Kelly was convicted with 5 years of imprisonment. In this case, Kelly had trusted the researchers of the HIV programme that his HIV status would be kept confidential and anonymous; Kelly's HIV status could be regarded as a 'valued thing X', according to Baier's conceptualisation of trust. Disclosing the HIV status of Kelly might be regarded as an example of an individual trusting the researcher, while at the same time the trustworthiness can be questioned. Professor Brown, who was responsible for the HIV research programme, stated: 'The thing that concerned me was that these samples were presented as part of a bona fide research programme and in confidence, and I was frankly appalled when this information was pulled out as part of this investigation, and there seemed to be nothing I could do about it.'[4] He added: 'As far as my own research is concerned, I wouldn't touch another molecular epidemiology investigation in Scotland unless there is some clarification of whether this seizure of material is or is not appropriate.'[4]

There is also some empirical evidence which supports the theory that FUB might have a negative impact on trust. A US

study investigated the perceptions and attitudes of (future) research participants about genome-wide association studies in 10 focus groups.[41] In every session of this study, distrust was expressed about the possibilities of the federal government to access research data for purposes other than research. The participants had two main concerns. The first was 'the potential for inappropriate use of data by law enforcement or national security agencies' and the second 'the possibility of a "tyrannical government" using such data for eugenics or other objectionable purposes'.[41] One participant said: 'I would trust researchers, but I don't trust the insurance industry, and I don't trust the government'[41] (p 92).

Another study also showed an impact on trust. A global survey of almost 9000 adults from the USA, UK, Canada and Australia asked participants about their attitudes and opinions regarding large genomic data sets and the donation of one's personal data.[42] 32.2% of participants indicated that they were concerned about the 'government potentially knowing something about me that I hadn't chosen to tell them'[42] and 18.2% were concerned about the police knowing something about them without their consent. The study also looked into the differences between the people who were willing to donate their DNA and medical information, and those who were not willing. Remarkably, there is not a very large difference between the group willing and unwilling to give their DNA when it comes to their concerns about the police knowing something: 17.2% and 23.8%, respectively. Interestingly, also 4050 participants (45.2%) stated that they were afraid their DNA would be copied and planted at a crime scene.[42]

By contrast, there is one study which suggests FUB will only marginally affect trust. In this study by Bexelius *et al*,[43] 810 inhabitants of Stockholm responded to a questionnaire. A majority of the respondents (88.1%) regarded it as acceptable for the police to gain access to genetic samples stored for healthcare purposes. Only 6.3% of participants indicated that this practice would have a negative impact on their trust. It is unclear whether these numbers are representative of a broader population. It should be noted that trust in government is relatively high in Sweden compared with other countries.

In conclusion, there are clear indications that FUB has a negative effect on trust, although the empirical evidence is too limited to estimate the size of the impact. Still, one could argue that *even* if the effects on patients' trust were very limited, FUB could still be ethically problematic on deontological grounds. For the debate on FUB, it is therefore important to address the principle of trust not solely from a consequentialist perspective. A deontological argument might put a greater emphasis on the value of trust in itself. Confidentiality and trust are thousands-year-old cornerstones of the physician–patient relationship. Constantine the African wrote around 1100 AD that a physician 'ought to keep to himself confidential information concerning the ailment, for at times the patient makes known to the physician things that he would blush to tell his parents'.[44]

Autonomy

Respect for patient's autonomy is a core principle of biomedical ethics, that is mainly operationalised through the requirement of informed consent.[45] In the context of FUB, one could argue that FUB cannot be justified, because no informed consent has been given for this usage. Indeed, it is highly plausible that in all of the above-described cases, the suspects were not aware their tissues could be used for forensic objectives, not to mention they had given consent for this.

There are even some criminal justice cases in which people have explicitly stated they *did not want* to give their bodily material to the authorities, and because of this reason, law enforcement decided to obtain the biological samples from a medical context. An example of this is the aforementioned Australian incest case; the police seized the Guthrie blood samples of children after their mother had refused to give permission to obtain blood directly from the children.[38] In this case, the mother of the children (and daughter of the suspect) explicitly *refused* to give consent. In the BTK killer case, too, there was no informed consent given by the suspect's daughter to obtain her cervical cell material. The police simply bypassed the daughter in the process. There could also be cases in which bodily material is obtained by law enforcement, but the person from whom the material is taken, and who had not given consent, turns out to be innocent; in that case, the harm that resulted from this should be weighed against the importance to potentially solve a crime.

With respect to a deceased suspect, it is obviously not possible to obtain informed consent, but still—as does apply to all the other cases—one cannot assume consent either. In the case of identification of a victim, rather than that of a suspect, this is different; in the case of victims, usually we can reasonably assume that the victim of a murder would have been wanted to be identified.

In all of the described cases in this article (see table 1), no informed consent was given by those concerned to access the bodily material. It has been argued that—when it is not possible to legally forbid relevant types of FUB—the second-best option is to limit FUB as much as possible, and, in addition, to inform the donors of bodily material about the possibility of forensic use.[3]

One might argue that a system could be developed in which informed consent about FUB is asked from anyone whose material is stored, which would make it justified to forensically use the material. However, this proposal is problematic. First of all, given the millions of tissue samples stored around the globe, it is simply infeasible to seek informed consent from everyone involved. Even if it were practically possible, it would take a lot of time and effort, and obstruct important biomedical research. However, perhaps the most important argument against implementing informed consent is that criminals can simply opt out and have their tissue samples destroyed. Thus, it will simply not be beneficial for the initial aim: the prosecution and investigation of crimes.

Justice

Finally, we briefly consider justice; another core principle of biomedical ethics.[18] With respect to the context of FUB, there might be at least two concerns regarding justice. They are both related to the concept of equality, which is a central component to almost all theories of justice. It dates back to Aristotle and entails that all equals should be treated equally and all unequals should be treated unequally.[18] In the context of FUB, the issue of equality concerns the individuals whose bodily material is stored in medical biobanks versus the individuals whose material is not stored in such biobanks. In many biospecimen archives in hospitals, the proportion of ill individuals is over-represented compared with healthy individuals. Therefore, giving police access to these biobanks will target ill individuals disproportionally; their material is more likely to be stored in such medical biobanks (which renders them more vulnerable for prosecution). Thus, individuals who are ill are treated in a *different* way than individuals who are not. In any case, they have a higher risk to be arrested. It does not seem fair that the criminal justice system could target ill people more than healthy people. The chance of

being prosecuted should not depend on whether or not one's kidney tumour is stored in a hospital's basement.

Second, as health problems are related to poverty,[46] allowing FUB might also disproportionately affect poor people, who are already under a greater risk to be targeted by police inquiries. There is, thus, a potential twofold inequality for ill individuals: first, the unequal risk of investigation and prosecution, and, second (but related), the unequal risk for poor people. In sum, there might be a problem with respect to the so-called *distributive* justice, which refers to the fair and equal distribution of responsibilities, rights and burdens within a society.[18] After the murder case of Anna Lindh, the Swedish Minister of Health declared that biobanks 'should only be used for research purposes. They are not police records, nor a register for social problems'.[6] Notably, the—controversial—population-wide genetic forensic database has far fewer problems with equality and distributive justice in comparison to FUB; as *all* citizens are in the database, there are almost no ethical problems from the perspective of equality.

Could individuals avoid these injustices? To some extent, an ill criminal might avoid going to the doctor for mild health issues, such as a cough, and thus prevent bodily material being taken and stored. But for more severe, life-threatening conditions, this does not seem to be feasible, as staying alive will often be an over-riding value for people. Second, requesting that your bodily material will be destroyed after it has been stored does not appear to be a (perfect) solution to the inequality—and therefore injustice—either. When individuals request their biological samples to be destroyed, this might draw the attention of law enforcement. Indeed, this is not as unlikely as it may seem, as a Swedish crime investigation has demonstrated. In that case, an extensive police investigation of nine sexual assaults showed that these offences were committed by the same man. However, the identity of this man, known in the media as 'Hagamannen', was not known. Therefore, police requested access to names and social security numbers from persons who had requested the destruction of their blood samples stored in the newborn screening blood database (which multiple people had done in the aftermath of the public outcry resulting from the biobank access in the Lindh case)—which was refused.[30]

To conclude, FUB might also result in issues regarding justice, mostly with respect to inequality and distributive justice.

DISCUSSION

We have discussed FUB from an ethical perspective, focusing on confidentiality, trust, autonomy and justice. The possible negative effects with respect to confidentiality, trust, autonomy and justice could be considered in light of possible criminal justice benefits. By attempting to balance ethical harms and criminal justice benefits, two issues are crucial: (1) whether there are alternatives to FUB, and (2) the urgency to solve the crime.

Before discussing these two issues, it should be noted that in many cases FUB will not be useful to solve a crime in the first place. This is because—for now at least—medical biobanks are not organised in a way that one can simply scan through an entire biobank to compare a DNA profile of a crime scene (in contrast to forensic genetic databases). Therefore, police will already need to have a suspect in view (an exception is the case in which they asked the names of those who had their specimens destroyed). When the suspect is known—and this brings us to the first point—often there are multiple good alternatives to obtain a DNA sample, such as obtaining it from a toothbrush, a discarded coffee cup or through familial testing. It might, for example, have been possible to find a discarded cigarette butt of the BTK suspect rather than accessing his daughter's Pap smear.

However, there will also be cases in which there is simply no alternative other than obtaining the *medical* tissue sample to provide the unequivocal evidence. An interesting case in this respect is that of Stephen Kelly (see the Trust section). Here, it is clear that there is no alternative evidence available to prove the suspect was already infected with HIV, other than obtaining the blood results from the HIV test.

The issue of alternatives is also relevant in the case of a deceased suspect. Regarding the Norwegian bank robbery, the suspect had already died of cancer before he came into the picture of law enforcement. Although it is unknown whether the suspect was cremated or buried after death, one might argue that—when we assume the man was cremated (and thus exhuming a body is not possible) and no DNA could be obtained from his former home—there is no alternative to obtaining the suspect's DNA other than accessing his tissue samples stored in the hospital where he received cancer treatment. The same applies to the Swedish suspect of the murder and dismemberment of Catrine da Costa.

Still, one could argue that even in these instances of deceased suspects, often alternatives do exist. For example, when a suspect has deceased, law enforcement might turn to parental testing of family members to match the DNA found at the crime scene (assuming that consent is given). Even when close relatives of the suspect have deceased too, there are possibilities to identify the suspect through distant relatives. With newly emerging DNA matching technologies, such as single-nucleotide polymorphism array techniques, it is possible to identify even ninth-degree cousins.[47] Add to this the rapidly expanding use of DTC genealogy databases and one might ask whether FUB might become largely superfluous in the near future. In the period August 2018 to August 2019, DTC genealogy databases have been used to identify suspects and missing individuals in more than 50 cold cases.[48] In addition, it has been argued that a genetic database needs to contain only 2% of a population to result in a third-degree cousin match to almost any person of the population.[49] It has even been hypothesised that by 2021, genotypes of more than 100 million people are in DTC databases and therefore finding a matching relative will become almost a complete certainty.[50] Thus, when the primary aim of the criminal investigation is the identification of a suspect, accessing DTC genealogy databases may be preferable—avoiding accessing *medical* material.[iii] When, however, the aim is not identification, but some other—such as the HIV testing of Stephen Kelly—the DTC genealogy databases will not be of any utility, since these databases can almost solely be used in the forensic setting for identification. Thus, in these cases accessing a medical biobank might still have a utility for law enforcement.

Regarding our second point, the *urgency* that the crime is solved should also be taken into account. In this context, time pressure is relevant; when there is a serial killer on the loose who kills someone every Wednesday morning, the urgency to find this criminal is much higher compared with a decades-old cold case. Although in an old case there are evidently also benefits that the crime is solved, primarily for the family of the victims or the victims themselves, there is less urgency for rapid action. As has been mentioned already above, breaching confidentiality is

[iii] Forensic use of DTC databases plausibly entails different ethical considerations than FUB, for example, regarding physician–patient confidentiality, and should therefore be discussed in a separate paper.

usually justified in the context of crime *prevention*, not the investigation or prosecution of that crime. Also in the Dutch container baby case, the level of urgency was considered. The National Institute for Public Health denied access to the newborn's blood sample, because—they argued—there was no serious danger for the child or for others at the time. However, some people might argue that the ethical problems of FUB are simply outweighed by the importance of crime solving.

The case examples have shown that regarding the urgency to solve the crime, the *severity* of the crime plays an important role as well. For example, the recently proposed Dutch legislation only allows FUB in the case of serious crimes, such as murder and rape. The article states that in these serious cases using the bodily material for forensic purposes is '(…) in the interest of society in general and of the victims and possible relatives in particular'.[34] This line of reasoning can also be recognised in the decision by the Scottish High Court in the HIV case. In the other FUB case examples police tend to turn to biobanks in the case of a horrendous and/or societal high-impact crime, such as the assassination of a politician, the most violent bank robbery in a country's history or the cruel dismemberment of a young woman. It can be questioned whether there was an urgent need to solve these crimes with respect to the risk of recidivism, or that the political and social pressure plays a more predominant role.

In sum, regarding the question whether FUB would be allowed, the availability of alternatives as well as the urgency (time pressure and severity of the crime) may well be important factors. With respect to time pressure, it might be the case that some good alternatives to FUB are less appealing, simply because they would take more time. Furthermore, one might argue that only weighing the harms and benefits of FUB will not be sufficient to explore the complete ethical debate on FUB. Indeed, those who take a more deontological position could argue that the possible negative effects of FUB with regard to confidentiality, trust, autonomy and justice must lead to the conclusion not to permit FUB, regardless of its potential for crime solving.

CONCLUSION

It is important that FUB is not only approached from a legal or law enforcement perspective, but also from a bioethics perspective as it concerns core issues in medical ethics. Our analysis shows that there are pressing ethical problems related to FUB concerning confidentiality, trust, autonomy and justice. In addition, the case examples make clear that legal systems deal with FUB in disparate ways. Since this paper aims to give an overview of ethical issues involved, our discussion of these concepts is not exhaustive. Further research, focusing on each of these topics, is needed to provide ethical guidance and to inform the public, legal, social and political debate. Although FUB apparently does not occur frequently at the moment, rapid technological developments in the field of genetics could make it more common in the near future. Ultimately, the aim would be to guide policy decisions on how to responsibly deal with FUB and to prevent hasty—and possibly unwise—decisions being made in the aftermath of a societal high-impact crime. Even a small number of high-profile cases may have a considerable impact on people's health behaviour and their perception of healthcare and its core values.

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